

Appendix E: Informed Consent Quick Reference Guide



Informed Consent Form for Active Follow-up Quick Reference Guide

Please read the Informed Consent Form before signing.

The Gulf Study is about the potential health effects of oil spill clean-up.

You already completed a survey about your experience in oil spill clean-up.

By joining the Active Follow-up part of the study, you agreed to do the following:

During the in-home visit -

1. Complete a 1-hour interview about your health, habits and other jobs
2. Allow an examiner to take your blood pressure, measure your height, weight, hips and waist, and test your lung function (if eligible)
3. Provide blood, hair, toenail, urine, and possibly saliva samples
4. Allow our staff to collect dust from your home

Throughout the study -

5. Update your contact information once a year
6. Complete a 30-minute telephone questionnaire every two years
7. Allow us to follow your health using state and national health records such as death certificates or cancer registries
8. Allow us to contact you about related health studies
9. Allow us to share your coded information with other qualified researchers.

Length of Study: The study will last at least 10 years. You may quit the study at any time.

Use of Information Collected: The information you shared will be used for research on the potential health effects of clean-up activities related to the Deepwater Horizon oil spill in the Gulf of Mexico. The consent form explains in more detail how we will use the information and samples you gave for this study.

Results of Tests: We will give you information about your blood pressure, body mass index, lung function, complete blood count (if measured), and urine glucose (sugar) level. If you want, we will also send any abnormal test results to your doctor or health clinic. We can refer you to a doctor or clinic in your area, if you want. We will send you regular reports that summarize study findings. We can only share results of tests done in approved certified clinical laboratories. Individual results of tests done in research labs will not be shared because their meaning will not be clear.

Benefits: You may benefit from getting the results of medical screening tests. These results will let you know if you might benefit from seeing a doctor. We can help you find a doctor or clinic if you do not have one. You will not receive other direct benefits. You may be proud to be part of a research study that may help others.

Risks: Some of the questions we ask may make you uncomfortable. There is a small risk of bruising or infection from the blood draw. The lung function test may cause coughing and a feeling of lightheadedness. If this occurs, they will go away shortly after the test. There is also a slight risk your private study information could become known to others. The consent form explains what we will do to keep that from happening.

Confidentiality: Every effort will be made to protect the information and samples you provide. The Gulf Study has a Certificate of Confidentiality that helps protect your information.

Costs: There are no costs to you other than your time.

Payment to Participants: If you complete the in-home visit, you will receive a \$50 gift card as a token of our appreciation. You may be eligible for other small gifts in the future.